



## Participation by conflict-affected and forcibly displaced communities in humanitarian healthcare responses: A systematic review

Ella Rass<sup>a</sup>, Michelle Lokot<sup>a</sup>, Felicity L. Brown<sup>b</sup>, Daniela C. Fuhr<sup>a</sup>, Michèle Kosremelli Asmar<sup>c</sup>, James Smith<sup>a</sup>, Martin McKee<sup>a</sup>, Ibrahim Bou Orm<sup>c</sup>, Joumana Stephan Yeretian<sup>c</sup>, Bayard Roberts<sup>a,\*</sup>

<sup>a</sup> Department of Health Services Research and Policy, London School of Hygiene and Tropical Medicine, London, United Kingdom

<sup>b</sup> Research & Development Department, War Child Holland, Amman, Jordan

<sup>c</sup> Higher Institute of Public Health (ISSP), Saint Joseph University of Beirut, Lebanon

### ARTICLE INFO

#### Keywords:

Participation  
Community  
Refugees  
Migration  
War  
Health  
Health systems

### ABSTRACT

**Background:** Community participation in health responses in humanitarian crises is increasingly promoted by humanitarian actors to support adoption of measures that are relevant and effective to local needs. Our aim was to understand the role of community participation in humanitarian health responses for conflict-affected populations (including forcibly displaced populations) in low- and middle-income countries and the barriers and facilitators to community participation in healthcare responses.

**Methods:** Using a systematic review methodology, following the PRISMA protocol, we searched four bibliographic databases for publications reporting peer-reviewed primary research. Studies were selected if they reported how conflict-affected populations were involved in healthcare responses in low- and middle-income settings, and associated changes in healthcare responses or health outcomes. We applied descriptive thematic synthesis and assessed study quality using study design-specific appraisal tools.

**Results:** Of 18,247 records identified through the database searching, 18 studies met our inclusion criteria. Various types of community participation were observed, with participation mostly involved in implementing interventions rather than framing problems or designing solutions. Most studies on community participation focused on changes in health services (access, utilisation, quality), community acceptability and awareness, and ownership and sustainability. Key barriers and facilitators to community participation included political will at national and local level, ongoing armed conflict, financial and economic factors, socio-cultural dynamics of communities, design of humanitarian responses, health system factors, and health knowledge and beliefs. Included studies were of mixed quality and the overall strength of evidence was weak. More generally there was limited critical engagement with concepts of participation.

**Conclusion:** This review highlights the need for more research on more meaningful community participation in healthcare responses in conflict-affected communities, particularly in framing problems and creating solutions. More robust research is also required linking community participation with longer-term individual and health system outcomes, and that critically engages in constructs of community participation.

### 1. Background

The number of people affected by humanitarian crises continues to increase, with the United Nations projecting that an estimated 235 million people will require humanitarian assistance and protection in 2021 (OCHA 2019). Those crises caused by armed conflicts are becoming more complex and protracted (Spiegel et al., 2010) and have given rise to 46 million internally displaced persons (IDPs) and 26 million refugees

displaced into other countries (UNHCR 2020). Tens of millions more people (exact figure unknown) live within conflict-affected areas. The vast majority of conflict-affected and forcibly displaced populations are in low- and middle-income countries (LMICs).

Conflict-affected people must be supported with timely, appropriate, and effective health responses. It is increasingly understood that these are more likely to succeed if there is meaningful participation by the communities affected (see Box 1 for definition of participation). A group of 18 UN and non-UN organisations involved in humanitarian relief has committed to “include the people affected by humanitarian crises and their communities in our decisions to be certain that the humanitarian

\* Corresponding author.

E-mail address: [Bayard.roberts@lshtm.ac.uk](mailto:Bayard.roberts@lshtm.ac.uk) (B. Roberts).

<https://doi.org/10.1016/j.jmh.2020.100026>

Received 3 December 2020; Received in revised form 5 December 2020; Accepted 5 December 2020

Available online 9 December 2020

2666-6235/© 2020 The Authors. Published by Elsevier Ltd. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>)

response is relevant, timely, effective and efficient” (IASC 2017). International norms, such as the Sphere Standards and the Core Humanitarian Standard, also emphasise the importance of community participation (Sphere 2020; CHS 2020).

**Box 1: Defining Community Participation**

There is not a standard definition of community participation in healthcare. Rather, it is an umbrella term that incorporates a wide range of concepts and activities, such as consultation, involvement, mobilisation or empowerment (WHO 2002; Preston et al., 2010; Rifkin, 2014; George et al., 2015; Rifkin 2009). For this review, we used the following combination of WHO definitions (WHO 2002):

- ‘Community’ can be defined as “a group of people who share an interest, a neighbourhood, or a common set of circumstances. They may, or may not, acknowledge membership of a particular community.”
- ‘Participation’ can be defined as “a process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change.”

Many commentators have argued, on the basis of normative considerations and reviews of the evidence, for community participation in planning, organising, operation and control of healthcare (George et al., 2015; Rifkin 2009; 2014; Haldane et al., 2019; Herrera et al., 2017; Preston et al., 2010; WHO 2008a, 2008b, 2002). The evidence from stable settings points to effective participation offering three key benefits: (i) ownership of services, which in turn may reduce the risk of poor implementation; (ii) just policies and programmes, including diverse perspectives; and (iii) improved effectiveness of policies and programmes by providing information relevant to local needs (Fung 2006;

George et al., 2015; Herrera et al., 2017; Rifkin 2009; Cyril et al., 2015; Prost and al 2013).

However, findings from studies in stable settings cannot necessarily be transferred to conflict-affected settings and populations given their distinct contextual factors, which may impact the design, implementation and effectiveness of community participation. These distinct contextual factors include ongoing or likely risk of violence and insecurity, forced displacement, language barriers, amplified individual and community suffering, damaged infrastructure and logistical challenges, limited resources, weakened health care systems and disrupted and often unpredictable provision of health care that is often delivered by humanitarian agencies operating on short-term planning and funding cycles.

Our study aims to understand the role of community participation in humanitarian health responses for conflict-affected populations (including forcibly displaced populations) in LMICs and the barriers and facilitators to community participation in healthcare responses. The specific objectives are to: (i) describe the types of community participation that occur in humanitarian healthcare responses; (ii) examine whether and how community participation has helped to improve humanitarian healthcare responses; (iii) identify barriers and facilitators when fostering community participation in humanitarian healthcare responses; and (iv) assess the quality of the published evidence.

**2. Methods**

We conducted a systematic review following the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA) (Moher et al., 2010), with the completed checklist provided in Online Annex 1.

The eligibility criteria included the following four categories: (1) process of community participation; AND (2) influence on healthcare responses or individual or population health; AND (3) forcibly displaced and other conflict-affected populations; AND (4) LMICs. The full inclusion and exclusion criteria are listed in Table 1 and definitions of key terms elaborated in Online Annex 2.

The following bibliographic databases were searched: MEDLINE, EMBASE, Global Health and PsycINFO. Both subject heading terms and

**Table 1**  
Inclusion and exclusion criteria\*.

Category	Included	Excluded
Population of interest	Individuals, groups and communities affected by armed conflict in LMICs (as defined by the World Bank (World Bank 2019)). LMICs were the focuses as the majority of crisis-affected populations reside in LMICs, and the contexts and resources for healthcare responses in LMICs are different to those in high-income countries. Conflict-affected populations include those remaining in areas affected by conflict, and those forcibly displaced from them as refugees and IDPs. Humanitarian crises included were events stemming from armed conflicts and wars that threaten the health and safety of a community. The time periods of humanitarian crises included acute, chronic, and recovery time periods.	Studies that take place in humanitarian contexts created by natural disasters. These were excluded as the responses are typically very different to those to armed conflict, most notably involving a generally much shorter time-period. Studies that included current or former military populations. Studies in high-income settings. For studies that include both conflict- and non-conflict affected populations, only included studies that provide disaggregated data for crisis-affected populations were included.
Intervention	Community participation in healthcare responses (see Box 1 or Online Annex 2 for definitions).	Studies only mentioning involvement of individuals from affected communities providing routine services/activities (e.g., clinicians, community health workers, peer educators etc.) and which do not describe, explore and present findings on the actual role of community-level participation.
Comparison	N/A	
Outcome measures	Changes in health services, health care, health systems or changes in individual or population-level health outcomes.	Studies only on nutrition. Studies only on water, sanitation and hygiene. Studies that do not describe changes in health services, care or individual or community-level outcomes. Editorials, commentaries, letters, reviews. Grey literature.
Study design	All quantitative and qualitative study designs.	
Publication type	Peer-reviewed empirical, primary research papers in academic journals, books or book chapters.	Grey literature.
Language	English language only.	Languages other than English.
Date	Papers published prior to mid-July 2020.	Papers published after mid-July 2020.

\*See also Online Annex 2 for definitions.

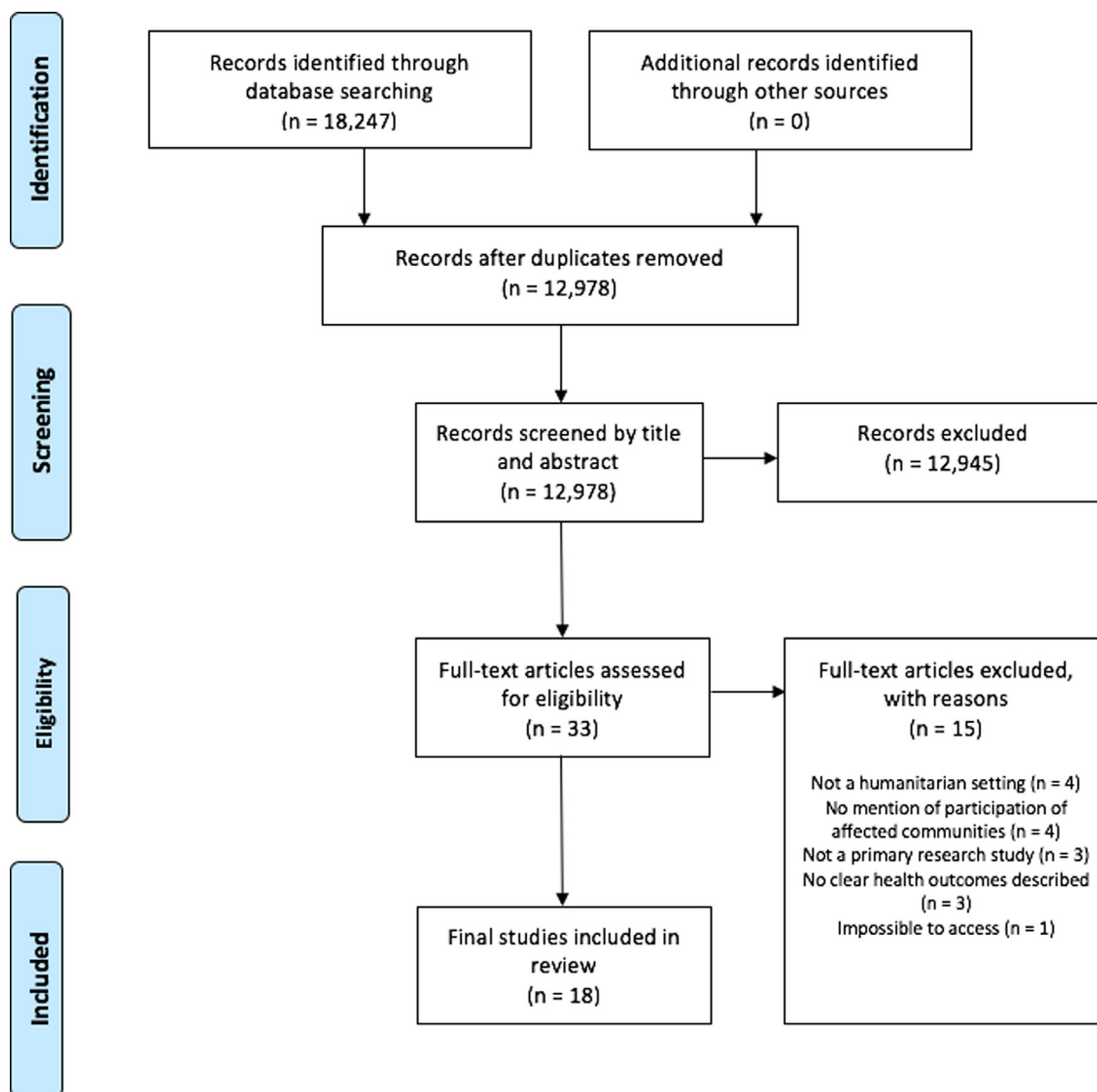


Fig. 1. PRISMA-P flow chart showing the selection process for studies.

free-text search terms were used, and the search terms and syntax are provided in Online Annex 3. References cited in the included peer-reviewed studies were examined for potentially relevant additional articles. Grey literature (e.g., from NGO reports) was excluded due to concerns over the quality (Blanchet et al., 2017).

Citations were imported from the bibliographic databases into End-Note for eligibility screening. Duplicates were removed, and remaining citations assessed by title and then by abstract by two independent screeners. A full text review of remaining studies was then conducted. Extracted variables included: author and date of publication, study design, geographic setting, study population characteristics, study objectives, types of participation, health outcomes of interest, influence of community participation on health care and outcomes, identified barriers and facilitators to participation, and study quality criteria.

A narrative synthesis was conducted given the heterogeneity of: contexts, study designs, interventions and outcomes measured, the expected qualitative nature of most of the data, and the exploratory nature of the review. Thematic synthesis was used within the framework of the research objectives.

For the quality appraisal, qualitative studies (not including case studies) and randomised control trials (RCTs) were appraised using the relevant Critical Appraisal Skills Programme checklists (CASP 2018a, 2018b). Case studies and surveys were appraised using relevant center

for Evidence-Based Management checklists (CEBMa 2020a, 2020b). See Online Annex 4 for the individual checklists.

### 3. Results

The database searches returned 18,247 citations (12,978 after duplicates were removed), which were reduced to 18 eligible studies (Adams et al., 2020; Custodio Espinoza et al. 2015; Erismann et al., 2019; Ghebreyesus et al., 1996; Habib et al., 2017; Ho et al., 2015; Kloos 1997; Kohli et al., 2012; Martini et al., 2019; Masumbuko Claude and Hawkes 2020; McMahon et al., 2017; Roddy et al., 2007; Sethi et al., 2017; Stepakoff et al., 2006; Steven et al., 2019; Tanaka et al., 2004; Teela et al., 2009; von Roenne et al. 2010). The screening results are shown in Fig. 1. An overview of the included studies is provided in Table 2.

Publication years ranged from 1996 to 2020, with most published between 2015 and 2020. Fourteen were in Sub-Saharan Africa, and the rest from the Middle East, Asia, or South America. Almost all study settings were either in chronic or protracted crises (nine studies) or post-crisis/early recovery (eight studies). One study spanned multiple time periods before, during and after a crisis. Four studies were with refugees. There were no studies looking at participation by refugees and host communities together. The remaining 14 studies were amongst general pop-

**Table 2**  
Overview of included studies.

Author, year	Country	Crisis type	Study population	Study design	Health focus	Main types of participation
(Adams et al., 2020)	Sierra Leone	Post-crisis/early recovery	General population	Qualitative	Mental health	Community forums
(Custodio Espinoza et al. 2015)	Peru	Post-crisis/early recovery	General population	Case study	Mental health	Community forums
(Erismann et al., 2019)	South Sudan	Chronic crisis	General population	Qualitative	Primary healthcare services	Community health committees; health services
(Ghebreyesus et al., 1996)	Ethiopia	Post-crisis/early recovery	General population	Case study	Malaria control	Community health committees; health services; community financing and infrastructure support
(Habib et al., 2017)	Pakistan	Chronic crisis	General population, incl. aged <5 years	RCT	Vaccinations (polio and others)	Health promotion
(Ho et al., 2015)	Democratic Republic of Congo	Chronic crisis	General population	Case study	General local health system	Community forums; community health committees
(Kloos 1997)	Ethiopia	Multiple time periods	General population	Case study	Primary healthcare services	Health services; community health committees; community financing support
(Kohli et al., 2012)	Democratic Republic of Congo	Chronic crisis	General population, with focus of outcomes on women	Case study	Sexual and gender-based violence	Health services; health promotion; health forums.
(Martini et al., 2019)	Mali	Chronic crisis	General population	Qualitative	Chronic diseases - diabetes and HIV/AIDS	Health committees
(Masumbuko Claude and Hawkes 2020)	Democratic Republic of Congo	Chronic crisis	General population	Cross-sectional survey	Ebola virus	Health promotion
(McMahon et al., 2017)	Sierra Leone	Post-crisis/early recovery	General population	Qualitative	Ebola virus	Community health committee; health service delivery; community financing and infrastructure support
(Roddy et al., 2007)	Angola	Post-crisis/early recovery	General population	Case study	Marburg virus	Health services
(Sethi et al., 2017)	Lebanon	Chronic crisis	Syrian refugees	Case study	NCDs - diabetes and hypertension	Health services
(Stepakoff et al., 2006)	Guinea	Post-crisis/early recovery	Refugees from Sierra Leone and Liberia	Case study	Mental health	Health services; health promotion
(Steven et al., 2019)	Democratic Republic of Congo	Chronic crisis	General population, with focus on women	Qualitative	Sexual and reproductive health	Forums; health services; health promotion
(Tanaka et al., 2004)	Tanzania	Post-crisis/early recovery	Refugees from Democratic Republic of Congo	Mixed methods	General health services	Health services; health promotion
(Teela et al., 2009)	Myanmar	Chronic crisis	General population	Qualitative	Maternal healthcare	Health services; community forums
(von Roenne et al. 2010)	Guinea	Post-crisis/early recovery	Refugees from Sierra Leone and Liberia, with focus on women	Case study	Reproductive health	Health services; health promotion; community financing support

ulations affected by conflict. No studies were identified specifically on IDPs, although a number of studies included IDPs within their populations.

Four main types of health issues were addressed. The first were specific communicable and non-communicable diseases including viral haemorrhagic fever outbreaks, malaria control, polio vaccination, diabetes and hypertension ( $N = 7$ ). The second related to sexual, reproductive or maternal healthcare and gender-based violence ( $N = 4$ ). The third involved access to, and quality of, primary health care and general health services ( $N = 4$ ). The fourth related to mental health conditions ( $N = 3$ ). Studies focused on healthcare service delivery generally, rather than other health system components.

Fifteen studies used qualitative methods, two used quantitative methods, and one used mixed-methods. Of the 15 qualitative studies, six were focus group discussions (FGDs) and/or key informant interviews (KIIs) with some document analysis, and nine were case studies looking

in-depth at specific contexts. Of the two quantitative studies, one was a cluster RCT and one a cross-sectional survey. The mixed-methods study used FGDs, KIIs and a cross-sectional survey.

Fig. 2 summarises the key themes related to types of participation, outcomes from participation, and barriers and facilitators to participation. These are described in turn.

### 3.1. Types of participation reported

The types of participation and how they were implemented is described below.

#### 3.1.1. Health service delivery

Eleven studies documented how community members were involved in delivering healthcare services to their own communities, in paid and

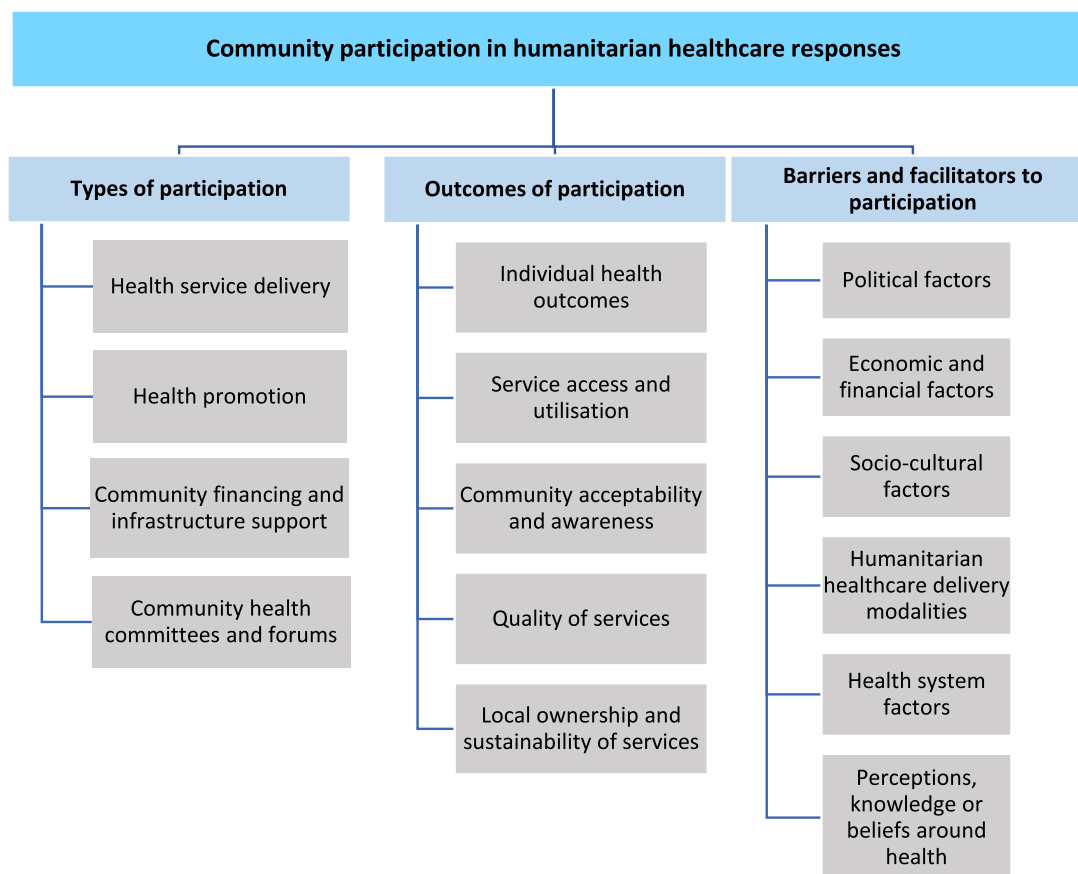


Fig. 2. Coding tree showing key themes of results.

unpaid roles. Their activities included involving and training community members to provide: psychosocial support and basic mental health care (Roddy et al., 2007; Sethi et al., 2017; Stepakoff et al., 2006); identification and management of those with risk factors for hypertension and diabetes (Sethi et al., 2017); supporting maternal, reproductive health and GBV awareness services (von Roenne et al. 2010; Kohli et al., 2012; Teela et al., 2009); and active disease finding for diarrhoea (Tanaka et al., 2004). Others described how communities elected village members for training and support to primary care services (Erismann et al., 2019; Ghebreyesus et al., 1996; Kloos 1997). One documented how community members were involved in a range of activities related to Ebola prevention and control in Sierra Leone (McMahon et al., 2017).

### 3.1.2. Health promotion

Nine studies documented how community members (including community leaders as facilitators and advocates) conducted health promotion activities. The four studies with refugee populations describe how local volunteers led community awareness campaigns (Stepakoff et al., 2006) or household-level tailored health promotion activities (Sethi et al., 2017; Tanaka et al., 2004; von Roenne et al. 2010). Community health promotion was the focus of four studies on control of specific diseases, including malaria, polio, Ebola, and Marburg Disease (Ghebreyesus et al., 1996; Habib et al., 2017; Masumbuko Claude and Hawkes 2020; Roddy et al., 2007). Community members were described as ‘social mobilisers’ within their own communities, galvanising change, facilitated by their understanding of beliefs and customs and to act as ‘bridges’ between foreign response teams and local communities (Habib et al., 2017; Masumbuko Claude and Hawkes 2020). Participatory and collaborative interactions to target health promotion were documented, such as sessions with parents (Habib et al., 2017), specific

genders (Habib et al., 2017) and affected families (Masumbuko Claude and Hawkes 2020), and SGBV survivors (Kohli et al., 2012).

### 3.1.3. Community financing and infrastructure support

Four studies discussed the contributions that communities themselves made towards financing healthcare responses (Ghebreyesus et al., 1996; Kloos 1997; McMahon et al., 2017; von Roenne et al. 2010). Community ‘revolving funds’, providing a means to fund purchases of drug and equipment costs, were established in Ethiopia with the aim of sustainability of programmes (Ghebreyesus et al., 1996; Kloos 1997). Many communities contributed time and resources during the Ebola response in Sierra Leone (McMahon et al., 2017). One study described how a self-run refugee reproductive health programme required its qualified nurses and midwives to contribute monthly membership fees, enabling similar programmes to be established once refugees could return home (von Roenne et al. 2010). Two studies demonstrated how communities participated in building health-related infrastructure, involving construction of animal corrals for vector control in Ethiopia (Ghebreyesus et al., 1996), and re-designing of existing health infrastructure in the Ebola response in Sierra Leone (McMahon et al., 2017).

### 3.1.4. Community health committees and forums

Six studies documented how communities were involved in planning, implementing, and evaluating health services in collaboration with the formal health system, through community health committees. Various terms were used to describe the committees, including ‘councils’ (Kloos 1997), ‘health management committees’ (McMahon et al., 2017), ‘health facility committees’ (Erismann et al., 2019; Ghebreyesus et al., 1996; Ho et al., 2015), or ‘patient associations’ (Martini et al., 2019). They could be a sub-committee of a general village development committee (Ho et al., 2015), or a more informal ‘go between’ the formal

health workers and communities (McMahon et al., 2017), providing training on health prevention activities (Erismann et al., 2019), or involved more directly in aspects of project management including budgeting and evaluation (Ghebreyesus et al., 1996; Kloos 1997), or patient-led associations contributing to policy formulation (Martini et al., 2019).

Community forums, or open invitation groups where residents (including patients) met to discuss matters, were documented in six studies. Forums encouraged open dialogue and mutual learning (Adams et al., 2020), discussion, and facilitated acceptance of health interventions (Erismann et al., 2019; Teela et al., 2009) or exchanges of ideas on programme design and strategy (Kohli et al., 2012). Examples of outcomes included 'scorecards' for health services to increase accountability and responsiveness to users (Ho et al., 2015), and development of a community mental health social transformation plan (Custodio Espinoza et al. 2015).

### 3.2. Outcomes of participation

#### 3.2.1. Individual health outcomes

Five studies sought to describe how community participation had influenced health outcomes. Two qualitative case studies noted positive changes in mental health from a community mental health project in Peru (Custodio Espinoza et al. 2015) and group therapy co-designed and run by local refugee counsellors in Guinea (Stepakoff et al., 2006). Another study reported positive effects on community health knowledge through the use of a refugee designed outreach programme in Tanzania (Tanaka et al., 2004). Two studies argued that involving patients with NCDs and chronic conditions in services formulation of national-level health policies led to better services (Sethi et al., 2017) and health outcomes (Martini et al., 2019). However, none of these studies were able to quantitatively attribute changes in health outcomes to community participation.

#### 3.2.2. Service access and utilisation

Three studies suggested that community participation increased access by communities to health services. This included community participation supporting: increased coverage in basic healthcare services in Ethiopia (Kloos 1997); improved access to emergency obstetric care in Myanmar by improving referral routes and co-operation between tiers of service providers (leading to anecdotal reports of a reduction in maternal deaths) (Teela et al., 2009); and improved scope and availability of reproductive health services increased in a refugee setting (von Roenne et al. 2010).

Community participation was linked to an increased utilisation of healthcare services in five studies. Three studies reported how changes in programme strategies (Habib et al., 2017; Kohli et al., 2012) and increased transparency and accountability (Ho et al., 2015) led to increased patient satisfaction resulting in increased service utilisation or uptake. One study reported improved home monitoring of diabetes and hypertension through the use of refugee community volunteers (Sethi et al., 2017). A qualitative study reported how a community-run programme in South Sudan on health rights led to increased demand for and utilisation of healthcare (Erismann et al., 2019). However, only one study quantified changes in uptake of health services (an RCT showing improved vaccination services in Pakistan) (Habib et al., 2017).

One study in Ethiopia noted how malaria treatment services were under-utilised by women and young children, partly attributed to a large gender imbalance of the participating community health workers (98% male) (Ghebreyesus et al., 1996).

#### 3.2.3. Community acceptability and awareness

Four studies described how some community participation improved acceptability of health care interventions (all were self-reported). Three studies reported how participation helped build community trust, awareness and support for both Ebola prevention and treatment activities, including acceptability of hospitalisation, better care-

seeking behaviour, easier case finding, and reduced stigma and rumours (McMahon et al., 2017; Roddy et al., 2007; Masumbuko Claude and Hawkes 2020). In the Democratic Republic of Congo, support by community leaders encouraged uptake of contraception and post-abortion care (Steven et al., 2019). However, the authors also noted how many community leaders held negative beliefs about women who had induced abortion and thus likely increased stigmatisation of them (Steven et al., 2019).

#### 3.2.4. Quality of services

Seven qualitative studies discussed how community participation led to perceived improvements in quality of healthcare services. This was reported as being achieved through community participation supporting: better training and increased confidence of healthcare workers (Kloos 1997; Kohli et al., 2012); better management of health facilities and improved health workers performance (Ho et al., 2015); and better understanding by health workers of community members' needs and improved patient-provider relationships (Adams et al., 2020; Ho et al., 2015; McMahon et al., 2017; Tanaka et al., 2004; von Roenne et al. 2010). No studies quantitatively measured how quality changed.

#### 3.2.5. Local ownership and sustainability of services

Four studies suggested evidence of increased sustainability of healthcare services, mainly attributed to increased local ownership and management of services, and improved healthcare knowledge of community members (Erismann et al., 2019; Sethi et al., 2017; Stepakoff et al., 2006; von Roenne et al. 2010). In two refugee settings, ownership and capacity building activities resulted in the initiation of similar healthcare programs in places of origin when refugees were able to return (Stepakoff et al., 2006; von Roenne et al. 2010).

### 3.3. Barriers and facilitators to participation

#### 3.3.1. Political factors

Eight studies identified political factors as both barriers and facilitators to community participation. A lack of political will was noted, with community participation in healthcare not viewed as a priority either at the national or local levels of government (Adams et al., 2020; Erismann et al., 2019; Kloos 1997). Furthermore, ongoing armed conflict and associated insecurity hindered community participation, particularly as populations were then dispersed (Habib et al., 2017; Kloos 1997; Teela et al., 2009; von Roenne et al. 2010). Political factors that facilitated community participation included socialist-orientated governments being more likely to give greater priority to rural health services and self-reliance, and incorporate community participation into strategic health plans such as in Ethiopia (Kloos 1997). In Mali, commitment by public authorities (encouraged by international donors) led to the involvement of patients with diabetes in formulating draft health policies (Martini et al., 2019). Two studies from the Democratic Republic of Congo and Ethiopia suggested that weak government influence in some conflict-affected areas may leave space for expanded community participation (Ho et al., 2015; Kloos 1997).

#### 3.3.2. Economic and financial factors

Seven studies discussed the impact that financial and economic factors had on community participation. Individual financial or in-kind compensation was a motivation for community participation in the Democratic Republic of Congo and Sierra Leone (Ho et al., 2015; Masumbuko Claude and Hawkes 2020; McMahon et al., 2017). Similarly, inadequate supplies and lack of payments, for example for contact tracing in Ebola responses, was a demotivating factor for community participation in Sierra Leone (McMahon et al., 2017). However, one study amongst refugees in Tanzania found the majority of health outreach staff would continue working if their allowances were reduced as their motivation was primarily altruistic rather than financial (Tanaka et al., 2004). Financial constraints, including short-term donor

funding, were identified as barriers for sustaining community participation programmes for NCDs in Mali (Martini et al., 2019), primary health care delivery in Ethiopia (Kloos 1997), and reproductive health services for refugee communities in Guinea (von Roenne et al. 2010).

### 3.3.3. Socio-cultural factors

Nine studies identified socio-cultural factors as having an impact on community participation. Awareness of cultural norms, practices, and perspectives by 'outsiders' encouraged communities to participate in humanitarian health responses (Roddy et al., 2007; Teela et al., 2009; von Roenne et al. 2010; Custodio Espinoza et al. 2015), while failure to recognise the cultural dynamics of a community was a major obstacle to community participation (Kloos 1997), and this was documented with some foreign-led responses to Ebola outbreaks (Masumbuko Claude and Hawkes 2020; McMahan et al., 2017). Appropriate gender balance amongst participants was seen as important (Custodio Espinoza et al. 2015; Ghebreyesus et al., 1996). Five studies mentioned the importance of understanding community members' individual circumstances, noting how they had to prioritise day-to-day survival, economic hardship, workloads, and coping with grief, over long-term planning and participation in health care responses (Erismann et al., 2019; Ghebreyesus et al., 1996; Kloos 1997; McMahan et al., 2017; Stepakoff et al., 2006).

### 3.3.4. Humanitarian healthcare delivery modalities

Nine studies raised the influence of humanitarian health care delivery modalities. It was noted that a rapid response (to a Marburg haemorrhagic fever epidemic) could exclude community participation in initial design and implementation (Roddy et al., 2007). In contrast, NGOs running community workshops to involve communities in the Ebola response in Sierra Leone helped to strengthen community participation (McMahan et al., 2017). One study also claimed that community participation, under the banner of governmental or United Nations agencies increased its credibility and so facilitated continued motivation for it by community members in the Ebola response in the Democratic Republic of Congo (Masumbuko Claude and Hawkes 2020).

Three studies discussed the effect of poorly coordinated humanitarian service delivery responses on community participation, with fragmentation of services, funding, organisations and staff turnover all impacting on community participation (Erismann et al., 2019; Kloos 1997; Sethi et al., 2017). In addition, disease-specific NGO programmes led to duplication of services and un-coordinated approaches, creating confusion and mistrust by communities (Erismann et al., 2019; Kloos 1997). Two studies speculated how privatised healthcare was not conducive to community participation (Kloos 1997; Sethi et al., 2017).

One study suggested that long term dependency on international humanitarian aid was a barrier to community participation, arguing it reduced communities or authorities taking ownership and initiative (Erismann et al., 2019). Two other studies found that communities affected by humanitarian crises recognised the importance of self-reliance which facilitated community participation (McMahan et al., 2017; Ghebreyesus et al., 1996).

The influence of refugee camp settings was also discussed. One study in Guinea reported that the uncertainty from living in refugee camps limited refugees' desire to participate in health responses (Stepakoff et al., 2006). However, in another study in a refugee camp in Guinea, organising community responses was logistically easier than in dispersed rural areas (von Roenne et al. 2010). A similar finding that organising community responses may have been easier in a camp setting than in dispersed urban or rural populations was observed amongst Syrian refugees in Lebanon (Sethi et al., 2017).

### 3.3.5. Health system factors

Six studies considered how functionalities and perceptions of the health system were barriers and facilitators to community participation. Poor local health services or gaps in services, leading to unmet

needs within the community, both encouraged and impeded participation. This galvanised action, with people wanting to participate in order to change the status quo (Habib et al., 2017; Tanaka et al., 2004; von Roenne et al. 2010). During the Ebola outbreak in Sierra Leone, recognition that the health system was damaged motivated people to participate because they could see an immediate and profound need, including the recognition of the government's limited human resource capacity (McMahan et al., 2017). Conversely in the same study, it was reported that people felt overwhelmed and frustrated at their country's broken health system, and thus discouraged from participating (McMahan et al., 2017). Furthermore, one study reported that the non-existent or poor service quality of mental health services acted as a barrier to community engagement (Adams et al., 2020).

A sense of pride towards community health facilities or loyalty towards admired health workers incentivised community participation (McMahan et al., 2017), alongside good communication between communities and healthcare workers (McMahan et al., 2017; Teela et al., 2009). Low trust between health staff and community members were identified as key barriers to community participation (McMahan et al., 2017; Tanaka et al., 2004). These findings demonstrate the importance of strong pre-existing relationships between communities and the healthcare providers to allow for better participation if future crises arise (McMahan et al., 2017).

### 3.3.6. Perceptions, knowledge or beliefs around health

The findings suggest that community members' beliefs and awareness on specific health conditions can inhibit or facilitate participation in responses related to those health conditions. In Sierra Leone, limited knowledge and negative beliefs on mental health impeded communities from participating in delivering mental health programming (Adams et al., 2020). Studies on Ebola outbreaks in the Democratic Republic of Congo and Sierra Leone showed that a strong understanding of Ebola facilitated community participation (McMahan et al., 2017; Masumbuko Claude and Hawkes 2020). One study reported how the framing of health topics may influence levels of community participation, with diabetes perceived by communities as being more clinical in need which resulted in low levels of community participation, whereas HIV/AIDS was seen as a social issue which resulted in higher levels of community participation (Martini et al., 2019).

## 3.4. Quality and strength of the evidence

All 18 studies clearly stated their aims and 17 used appropriate designs. Of the seven qualitative studies (excluding the case studies), only five mentioned ethical issues. All used appropriate recruitment strategies for qualitative research (purposive or snowball sampling). Four of the studies considered the relationship between researcher and participant and accounted for the researcher's perspective. For the majority of the case studies, it was difficult to tell whether the methods were valid or reliable, although six seemed to have more than one researcher analysing the data, which may have increased reliability. Of the quantitative studies, the RCT was of 'high' quality overall in terms of randomisation, allocation and follow-up, and precision. For the cross-sectional surveys, in one of them it was difficult to discern the recruitment strategy and selection bias could have been introduced. Neither survey mentioned sample size and power considerations or response rates. See Online Annex 4 for tables reporting the detailed results of the quality appraisal.

An additional observation (not captured through the quality appraisal checklists) was that the studies may have been affected by social desirability bias, particularly if participants were dependant on services offered as part of the project (e.g., by an NGO) and thus have provided answers they believed would support and sustain services or the NGO's presence. However, none of the studies in this review considered this. Thus, the critical issue of power relations between potentially

dependant populations and NGOs or researchers was not adequately addressed in the studies.

It is also important to note that many studies gave limited detail on the types and mechanism of participation, and only five of the eighteen studies explicitly examining the complex nature and meaning of community participation (Custodio Espinoza et al. 2015; Ho et al., 2015; Kloos 1997; Martini et al., 2019; Tanaka et al., 2004). In addition, despite some studies claiming improvements in health outcomes from community participation activities, the study designs used did not support measurement of attribution.

#### 4. Discussion

To the best of our knowledge, this is the first systematic review exploring community participation in health care responses amongst forcibly displaced and other conflict-affected populations in LMICs. The findings, while limited by the low volume and quality of the evidence, suggest that community participation can strengthen humanitarian health responses in the form of improved acceptability, awareness, access, quality, and sustainability of health services. Common barriers and facilitators to participation included political will, economic and financial factors, understanding of socio-cultural dynamics in communities and between communities and implementing organisations, humanitarian healthcare delivery modalities, health system factors, and health perceptions, knowledge and beliefs.

There are a number of gaps with the evidence identified. In terms of populations, there were only four studies involving refugees. There were also no studies examining participation of both refugee and host communities together, despite concerns about tensions and inequities in health care delivery between refugee and host communities. There were also no studies specifically with internally displaced persons.

With regards to other gaps, for the evidence on the effects of community participation on health outcomes there were considerable limitations with the study designs and methods employed to attribute changes due to community participation. Only one study tested the effectiveness of community participation using an experimental study design, and this limited use of experimental study designs reflects systematic reviews on community participation from stable settings (Crawford et al., 2002; George et al., 2015; Preston et al., 2010). Of those other studies that reported changes in health outcomes, the connection between community participation and health outcome was not clearly elucidated. There remains a clear need to scrutinise how community participation contributes to health outcomes. While this may be achieved through the use of experimental study designs, it should also be recognised that community participation is a social process (Rifkin 2009; 2014), and this requires in-depth exploration of the diversity of experiences and perceptions of those involved in all aspects of humanitarian health response. Many of the studies included in this review used short- to medium-term timeframes which may reflect the short-term funding and implementation cycles common for humanitarian health activities. These limited timeframes impede both measuring health effects of interventions but also the development of meaningful relationship-building between communities and service providers and undermine the opportunity to engage participatory approaches to both programming and research. While the challenges in conducting research in conflict-affected contexts should also be acknowledged, there are many examples of high-quality studies on other health topics in humanitarian contexts (Blanchet et al., 2017), and so it should absolutely be possible to conduct the rigorous research required on community participation by conflict-affected communities.

There was limited engagement in the studies on the concept of community participation, with only a few studies examining the complex nature and meaning of community participation (Custodio Espinoza et al. 2015; Ho et al., 2015; Kloos 1997; Martini et al., 2019; Tanaka et al., 2004). In-depth consideration, analysis, and theorisation of the concept of community participation is required to avoid super-

ficial approaches. This also requires engagement with the role of historically anchored and colonial power relations which are pertinent in shaping the structures, activities, and actor relationships within humanitarian programming and research. In addition, while most of the studies detailed community participation in delivering interventions, few studies engaged communities in identifying or framing problems, or designing or evaluating health interventions themselves, which may involve a deeper level of participation and ownership from the community. For example, a number of studies documented health promotion and while this does constitute a form of community participation, it is still often applied without the co-design of key messages and approaches with target communities, and as such forms what Brown & Donini describe as “information provision”: the least empowering process of engagement in humanitarian praxis (Brown and Donini 2014).

There was also a failure across many of the studies to critically examine and situate their research findings. For example, on how power hierarchies could have influenced the quality and means of participation, exemplified by an over-reliance on community leaders as the means of community participation rather than ensuring diverse representation of other community members who do not hold leadership roles. This is particularly important to consider in patriarchal cultures and gender power imbalances. Community leaders in positions of power are most likely men and may not appreciate or understand fully the needs of those with less power, specifically women. Communities may also be fragmented religiously, ethnically, culturally, and linguistically, with certain groups having greater power over others and this issue was rarely addressed in the studies identified in our review. Local socio-cultural power differentials amongst various community members receiving humanitarian aid and humanitarian actors should be more widely considered (Hilhorst and Jansen 2010).

Risks or unintended consequences of community participation were touched upon by only two of the studies in this review (Ghebreyesus et al., 1996; Steven et al., 2019). The most notable example was how induced abortion stigma was reinforced through the engagement of male community leaders who had pre-conceived negative views of induced abortion (Steven et al., 2019). This potentially caused further isolation and stigmatisation to affected women. This example demonstrates that the quality of participation as well as the nature of actors who participate play a critical role in the outcomes of participation. There is a clear need for awareness of programme implementers and researchers to understand contextual nuances in order to do no harm and be inclusive of a variety of community voices, particularly women. Unintended consequences of community participation have been noted in elsewhere, particularly that of ‘consultation fatigue’ where communities and individuals are repeatedly exposed to successive waves of requests for participation (Cyril et al., 2015). This fatigue is likely to be magnified in humanitarian crises and forced migration settings, particularly with more superficial attempts at community participation.

There was also a common failure in the studies for researchers to critically examine their findings. For example, there was limited engagement in power hierarchies between researchers (including some who worked for NGOs providing health services to the communities) and their study respondents from affected communities. There was also little reflexivity by researchers on how their own positions and biases may have influenced their studies (as also noted in studies in stable settings (Preston et al., 2010)). Such critical examination is key to supporting efforts to decolonise global health research.

##### 4.1. Review limitations

The exclusion of non-English papers and use of only four bibliographic databases meant that potentially relevant studies could have been missed, particularly in fields outside of health. However, other reviews suggest there is a limited number of non-English language studies in the humanitarian health literature (Blanchet et al., 2017). Grey literature is commonly produced by humanitarian NGO but it was not



included, and this exclusion was due to quality concerns with grey literature in such settings (Blanchet et al., 2017).

## 5. Conclusions

This systematic review identified a limited quantity and quality of evidence on community-level participation in humanitarian health responses, but findings suggest benefits from community-level participation for individual health outcomes and health service access, utilisation, quality, acceptability and sustainability. Key facilitators and barriers were also described. However, most models of community participation were rather limited, and more comprehensive approaches should be considered. In addition, the overall strength of evidence was low. There is a need for higher quantity and quality of research and greater critical engagement by researchers to help strengthen understanding, implementation and effectiveness of participation by conflict-affected communities in health care responses.

## 6. CRediT authorship contribution statement

ER and BR conceived the original study. ER led the design, screening, extraction, analysis and writing. BR, DF, JS double screened. All authors contributed to writing, review and editing.

## Declaration of competing interest

The authors declare no conflict of interest.

## Statement of ethical approval

Ethical approval was not required for this paper as all data used were in the public domain.

## Statement of funding

This work was supported by UK Research and Innovation as part of UKRI Collective Fund Award UKRI GCRF Development-based approaches to protracted displacement, grant number ES/T00424X/1.

## Supplementary materials

Supplementary material associated with this article can be found, in the online version, at [doi:10.1016/j.jmh.2020.100026](https://doi.org/10.1016/j.jmh.2020.100026).

## References

- Adams, B., Vallieres, F., Duncan, J.A., Higgins, A., Eaton, J., 2020. Stakeholder perspectives of Community Mental Health Forums: a qualitative study in Sierra Leone. *Int. J. Ment. Health Syst.* 14.
- Blanchet, K., Ramesh, A., Frison, S., Warren, E., Hossain, M., Smith, J., Knight, A., Post, N., Lewis, C., Woodward, A., Dahab, M., Ruby, A., Sistenich, V., Pantuliano, S., Roberts, B., 2017. Evidence on public health interventions in humanitarian crises. *Lancet* 390, 2287–2296.
- Brown, D., Donini, A., 2014. Rhetoric or Reality? Putting Affected People at the Centre of Humanitarian Action.
- CASP. 2018a. 'CASP: qualitative checklist', critical appraisal skills programme. <https://casp-uk.net/casp-tools-checklists/>.
- CASP. 2018b. 'CASP: randomised controlled trials checklist'. <https://casp-uk.net/casp-tools-checklists/>.
- CEBMA. 2020a. 'Critical Appraisal of a Case Study', Center for Evidence-Based Management. <https://cebma.org/resources-and-tools/>.
- CEBMA. 2020b. Critical appraisal of a survey, Center for Evidence-Based Management. <https://cebma.org/resources-and-tools/>.
- CHS. 2020. 'Core humanitarian standard', Accessed 14/09/2020. <https://corehumanitarianstandard.org/>.
- Crawford, M., Rutter, D., Manley, C., Weaver, T., Bhui, K., Fulop, N., Tyrer, P., 2002. Systematic review of involving patients in the planning and development of health care. *BMJ* 325.
- Custodio Espinoza, E., Rivera-Holguin, M., Seminario Pacheco, M., Arenas Sotelo, E., Ur-ruchi Bejar, P., 2015. 'Women's participation in a postconflict community in Peru. (Special Issue: community psychology and the need for community participation in Peru.)'. *J. Prevent. Intervent. Commun.* 43, 279–290.
- Cyril, S., Smith, B., Possamai-Inesedy, A., Renzaho, A., 2015. Exploring the role of community engagement in improving the health of disadvantaged populations: a systematic review. *Glob Health Action* 8.
- Erismann, S., Gurler, S., Wieland, V., Prytherch, H., Kunzli, N., Utzinger, J., Peterhans, B., 2019. Addressing fragility through community-based health programmes: insights from two qualitative case study evaluations in South Sudan and Haiti. *Health Res. Policy Syst.* 17, 20.
- Fung, A., 2006. Varieties of participation in complex governance. *Public Adm. Rev.* 66, 66–75.
- George, A., Mehra, V., Scott, K., Sriram, V., 2015. 'Community participation in health systems research: a systematic review assessing the state of research, the nature of interventions involved and the features of engagement with communities'. *PLoS ONE* 10, e0141091.
- Ghebreyesus, T.A., Alemayehu, T., Bosman, A., Witten, K.H., Teklehaimanot, A., 1996. Community participation in malaria control in Tigray region Ethiopia. *Acta Trop.* 61, 145–156.
- Habib, M.A., Soofi, S., Cousens, S., Anwar, S., Haque, N.U., Ahmed, I., Ali, N., Tahir, R., Bhutta, Z.A., 2017. Community engagement and integrated health and polio immunisation campaigns in conflict-affected areas of Pakistan: a cluster randomised controlled trial'. *The Lancet Global Health* 5, e593–e603.
- Haldane, V., Chuah, F., Srivastava, A., Singh, S., Koh, G., Seng, C., Legido-Quigley, H., 2019. Community participation in health services development, implementation, and evaluation: a systematic review of empowerment, health, community, and process outcomes. *PLoS ONE* 14, e0216112.
- Herrera, C., Lewin, S., Paulsen, E., Ciapponi, A., Opiyo, N., Pantoja, T., Rada, G., Wiysonge, C., Bastias, G., Garcia Marti, S., Okwundu, C., Peñaloza, B., Oxman, A., 2017. 'Governance arrangements for health systems in low-income countries: an overview of systematic reviews'. *Cochrane Database Syst. Rev.*
- Hilhorst, D., Jansen, B., 2010. 'Humanitarian space as arena: a perspective on the everyday politics of aid'. *Dev. Change* 41, 1117–1139.
- Ho, L.S., Labrecque, G., Batonon, I., Viviana, Salsi, Ratnayake, R., 2015. Effects of a community scorecard on improving the local health system in eastern Democratic Republic of Congo: qualitative evidence using the most significant change technique. *Confl. Health* 9.
- IASC. 2017. 'A participation revolution: include people receiving aid in making the decisions which affect their lives', IASC, Accessed 23/09/2020. <https://interagencystandingcommittee.org/a-participation-revolution-include-people-receiving-aid-in-making-the-decisions-which-affect-their-lives>.
- Kloos, H., 1997. Primary health care in Ethiopia under three political systems: community participation in a war-torn society. *Soc. Sci. Med.* 46, 505–522.
- Kohli, A., Makambo, M.T., Ramazani, P., Zahiga, I., Mbika, B., Safari, O., Bachunguye, R., Mirindi, J., Glass, N., 2012. 'A Congolese community-based health program for survivors of sexual violence'. *Confl. Health* 6.
- Martini, J., Tijou-Traore, A., Mahieu, C., 2019. 'Chronic patient as intermittent partner for policy-makers: the case of patient participation in the fight against diabetes and HIV/AIDS in Mali'. *BMC Public Health* 19.
- Masumbuko Claude, K., Hawkes, M.T., 2020. 'Ebola crisis in Eastern Democratic Republic of Congo: student-led community engagement'. *Pathog. Glob. Health* 114, 218–223.
- McMahon, S.A., Ho, L.S., Scott, K., Brown, H., Miller, L., Ratnayake, R., Ansumana, R., 2017. We and the nurses are now working with one voice: how community leaders and health committee members describe their role in Sierra Leone's Ebola response. *BMC Health Serv. Res.* 17, 495.
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D.G., Group, Prisma, 2010. 'Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement'. *Int. J. Surg.* 8, 336–341.
- OCHA. 2019. 'Global Humanitarian Overview 2020.' In: Geneva: United Nations Office for the Co-ordination of Humanitarian Affairs.
- Preston, R., Waugh, H., Larkin, S., Taylor, J., 2010. 'Community participation in rural primary health care: intervention or approach? A systematic review'. *Aust. J. Prim. Health* 6, 4–16.
- Prost, A., et al., 2013. Women's groups practising participatory learning and action to improve maternal and newborn health in low-resource settings: a systematic review and meta-analysis'. *Lancet* 381, 1736–1746.
- Rifkin, Susan B., 2009. 'Lessons from community participation in health programmes: a review of the post Alma-Ata experience'. *Sci. Direct* doi:10.1016/j.inhe.2009.02.001.
- Roddy, P., Weatherill, D., Jeffs, B., Abaakouk, Z., Dorion, C., Rodriguez-Martinez, J., Palma, P.P., de la Rosa, O., Villa, L., Grovas, I., Borchert, M., 2007. The medecins sans frontieres intervention in the Marburg hemorrhagic fever epidemic, Uige, Angola, 2005. II. Lessons learned in the community. (Special Issue: filoviruses: recent advances and future challenges.) *J. Infect. Dis.* 196, S162–S167.
- Sethi, S., Jonsson, R., Skaff, R., Tyler, F., 2017. 'Community-based noncommunicable disease care for Syrian refugees in Lebanon'. *Global Health Sci. Pract.* 5, 495–506.
- Sphere. 2020. 'Sphere Standards', Accessed 14/09/2020. <https://www.spherestandards.org/>.
- Spiegel, P.B., Checchi, F., Colombo, S., Paik, E., 2010. 'Health-care needs of people affected by conflict: future trends and changing frameworks'. *Lancet* 375, 341–345.
- Stepakoff, S., Hubbard, J., Katoh, M., Falk, E., Mikulu, J.B., Nkhoma, P., Omagwa, Y., 2006. 'Trauma healing in refugee camps in Guinea: a psychosocial program for Liberian and Sierra Leonean survivors of torture and war'. *Am. Psychol.* 61, 921–932.
- Steven, V.J., Deitch, J., Dumas, E.F., Gallagher, M.C., Nzau, J., Paluku, A., Casey, S.E., 2019. "Provide care for everyone please": engaging community leaders as sexual and reproductive health advocates in North and South Kivu, Democratic Republic of the Congo'. *Reprod. Health* 16, 98.
- Tanaka, Y., Kunii, O., Okumura, J., Wakai, S., 2004. 'Refugee participation in health relief services during the post-emergency phase in Tanzania'. *Public Health* 118, 50–61.

- Teela, K.C., Mullany, L.C., Lee, C.I., Poh, E., Paw, P., Masenior, N., Maung, C., Beyrer, C., Lee, T.J., 2009. 'Community-based delivery of maternal care in conflict-affected areas of eastern Burma: perspectives from lay maternal health workers'. *Soc. Sci. Med.* 68, 1332–1340.
- UNHCR. 2020. 'Figures at a glance', UNHCR, Accessed 02/12/2020. <https://www.unhcr.org/uk/figures-at-a-glance.html>.
- von Roenne, A., von Roenne, F., Kollie, S., Swaray, Y., Sondorp, E, Borchert, M., 2010. Reproductive health services for refugees by refugees: an example from Guinea. *Disasters* 34, 16–29.
- WHO. 2002. "Community participation in local health and sustainable development: approaches and techniques." Geneva: World Health Organization.
- WHO. 2008a. "The report of the commission on the social determinants of health." Geneva: World Health Organization.
- WHO. 2008b. *The World Health Report 2008: primary health care: now more than ever.* Geneva: World Health Organization.
- World Bank. 2019. 'World Bank country and lending groups: country classification data', Accessed 10/07/20. <https://datahelpdesk.worldbank.org/knowledgebase/articles/906519>.